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ABSTRACT

A case study is presented of Westport Associates, a corporation in Westport, Massachusetts, which operates small group homes for formerly institutionalized men and women with severe disabilities. Westport Associates was founded to create the antithesis of an institution, to treat residents as individuals worthy of respect, and to offer residents choices in their lives. Strategies were developed to ensure that the men and women felt part of a home and not simply as people who were being managed by a system. The case study presents biographical information about each of the residents. It also reports on the Medicaid-funded day program attended by the group home residents, other community activities attended by the residents, the obstacles to developing friendships with nondisabled community members, staffing patterns, costs associated with operating the homes, and changes evident in each of the residents due to their group home experience. (JDD)

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Center on Human Policy

SMALL HOMES: A CASE STUDY OF WESTPORT ASSOCIATES

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SMALL HOMES:
A CASE STUDY OF WESTPORT ASSOCIATES

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December 1987

This is one of a series of reports on programs and services that support people with severe disabilities in the community. The purpose of the series is not to evaluate programs or services, but rather to describe innovative practices for integrating people with disabilities into community life.

Small Homes:

A Case Study of Westport Associates

Initiation: Finding a Purpose

When she moved to Massachusetts, Sheila St. Auben didn't know for sure what she wanted to do with her life. So she decided to attend graduate school. At first, she thought she might just take a course or two, but before she knew it she was matriculated. She had done some volunteer work in college with people labelled retarded. She thinks it may have been something in that experience that drew her to a course on the psychology of mental retardation.

This course was taught by a man who had been a psychologist at the Dever State School for over 40 years. He offered students the choice of completing a term paper for the course or of volunteering at the Dever institution. Sheila decided to volunteer:

> I hated writing term papers so I figured I would go to this place and be a volunteer. I pictured the institution as being made up of little cottages with maybe 4 or 5 little kids who were retarded living in them, with house mommies and house daddies. And everyone was going to be thrilled to see this volunteer person showing up. I had no idea what was going to happen to me.
>
> When I drove up I found these horrible L shaped buildings, brick, large. I went to building 3 where I was supposed to go. I am knocking on the door. The door is locked.

Finally someone comes and lets me in. "Who are you?" the person asked, hostile. This was a long time ago (15 years ago), before it was common for people to come in and out of the institution. I couldn't believe people didn't know who I was, why I was there. They weren't happy to see me. Finally, when I kept explaining what I was doing there, they took me downstairs to the basement day hall. They unlocked the door and sort of tossed me inside and locked the door behind me. There were about 40 retarded men in that room in various states of undress. Nobody was buttoned or zipped. Many didn't have pants on. They didn't do anything bad to me; they just overwhelmed me. I stayed in there for about an hour trying to figure out what to do. There were no materials. No chairs. No tables. They were talking to me and I was trying to understand what they were saying. I wasn't scared, I was just confused and upset.

About an hour later somebody unlocked the door and let me out. I went home thinking what kind of a place is this? I can't go back. I'll write a term paper. The next week I went back. I really got into it. I liked the people. When Summer came, I went every afternoon instead of just once or twice a week.

It wasn't long before Sheila was hired to set up programs in the institution school. But as much as she liked the job, she continued to feel out of place. Then one night another staff person invited her to come and hear a man by the name of Gunnar Dybwad give a talk on institutions. That night changed her life:

> It was like a light bulb going on in my head. I lived in Westport Mass. at the time and I used to go home and think there is a concentration camp (Dever) only about 20 miles from here and I don't do anything about it. I come home and climb into my nice clean bed every night and I don't do anything about it.

She became a vocal critic of the institution. She began to take residents home with her on weekends. She asked questions and criticized policies. Within a year and a half of hearing Gunnar Dybwad's talk, she was fired and, eventually, banned from the grounds of the institution. A year later she began to work in the Department of Education, developing education programs, many of them in the community, for Dever residents. From this position she would go on to develop Westport Associates.

Getting Involved

In the late 1970s, a state official pleaded with Sheila to establish a community living organization:

> David Walter was the MR Director at Fall River. All Summer long he followed me around, down to the sand dunes, down to the beach. Finally he said, just come back to Dever and see some of the people who are on the waiting list. It was 1980 and a lot of people were waiting. He wanted me to incorporate and serve 10 people.

Sheila accepted the challenge because of the institution. She thought she could create something better for people outside of the institution. The idea of working for herself, controlling

her own hours and, more importantly, the quality of her own program was appealing. But most of all she believed she would enjoy working with and for the 10 people. In that sense this was not a job, rather it was doing what she liked to do.

When she visited Dever she met many of the same people she had known for years. She saw 20 or 30 people who were eligible to move out. One of these people was new to her and struck her attention:

> His name is Leonard. He is a very severely handicapped person physically. I hadn't met him before because he was in a back ward, baby ward they called it, although they weren't babies. These were people who didn't move. They were in cribs. They were so physically handicapped. I was amazed by him. This person was totally intact, his mind. And he hadn't been out of this building in about 10 years. He was lying in a crib. He didn't even have a wheelchair. When I talked to him, he couldn't talk back. He has such severe cerebral palsy that he can't speak. But he speaks with his eyes, and he was doing yes and no with me through a whole conversation. I just couldn't believe he was in this prison. I wanted to prove that he could live outside. I wanted to do something with physically handicapped people because no one else was.

Sheila recruited a former co-worker from the Education Department to start Westport Associates with her. His name is Steve Murphy. Sheila would be the Director; Steve would be program director. In a matter of months, in fact in record time,

they wrote a proposal, got incorporated, and were funded. They hired a part-time bookkeeper to keep the financial records.

Getting Started

Between April 6th and September 12th, they found three houses to rent, hired and trained group home staff, and were ready to start. They were determined not to recreate the institution in the community, though they could not always control what happened concerning their program. A newspaper, for example, ran a story about Westport Associates that referred to the 10 residents as "patients." "We don't call people patients", Steve explained. "We never use the word patients. But there it was, right in the paper." Similarly, they did not operate the day programs into which the residents were required to be enrolled, and so they had no control over their quality. But in matters they did control, they began to create a striking counterpoint to the institution.

The concept of escaping the institution was conscious. It was manifested in the transition plans they developed for each of the ten.

> We took pictures of the house for the four women, for example. We wrote on the bottom, Kathy's new house, Jill's new house,...and we went together to visit each of the women to try to explain to them what was going to happen to them, that this was what we had in mind for them, that this could be their new house. If they wanted to live there, they were going to move. We gave them the pictures. Kathy had only

seen us once. We didn't even know if she understood what we were saying. We gave her the picture, saying it is going to be your new home. "es, es," she said. We came back two weeks later to see her again. The minute she saw me she went running back to this locker, opened it, and whipped out that picture and came running up to me. They understood. We did that with everybody. It was kind of nice. We liked going there and taking pictures and bringing them up. It was really extraordinary how organized we were. We had charts or calendars, each day filled in. The next part of the transition plan was for us and for the staff to go up there and spend time with them and just get them (the residents) familiar with us. Eventually the staff would take them out for a ride and ice cream and then it was out to lunch and shopping, down to see the house and then to do things in the house and have dinner in the house or spend an afternoon there. It was pretty rigorous. They would be down there two or three times in a week, and part of the weekend. It just kept lengthening until the week we moved in. Actually, they had slept over there and gone to work from there even before they moved in.

Making Houses Into Homes

Creating the antithesis of an institution involved treating people as occupants of their own homes, as people who deserved respect, to be treated as individuals, to have choices in their lives. The staff had to share these values. Initially, Sheila

and Steve looked for college educated people to live in the homes with the residents. They found two of the first three not respectful enough of the residents; Steve and Sheila fired them. Steve notes that when either he or Sheila notice that they haven't visited one of the three houses in a couple of days, it is usually a sign that they are not being made to feel welcome at the home and that usually is a sign that a staff person does not want them around. "I can usually tell," Steve explains, "what staff will work out and which can't. If we both find that our schedules are beginning to avoid a house, that usually means we are not comfortable with the staff." Being comfortable means having staff who really like the residents.

What kind of staff do work out? "I don't look for college degrees anymore" Sheila explains, "and I don't look so much for experience in other places anymore either because some of these experiences contradict what we are trying to do." Yet I did meet one college student and one college graduate on the staff and several others who had had <u>other</u> experiences, even contradictory experiences such as working as attendants in institutions and in private residential schools. The skills that Sheila and Steve look for are "good homemaking skills, someone who can run a home, cooking, nutrition, budgeting, shopping, someone who can take care of house plants, who can sew, and someone who can teach people things." They also want people who have plenty of energy, their own interests and, if possible, lots of friends and family themselves. Sheila emphasizes that this is not a refuge for people who are lonely or who want to find themselves. In other

words it requires someone who is good at building a sense of community.

Westport Associates pays well, compared to most private agencies: $19,000 per year for a full-time house coordinator who is at the house from 3:00 P.M. on Mondays until 9:00 A.M. Fridays. Some of the coordinators have been employed for three or four years. Staff who work on weekends, 8:00 Friday afternoons until 9:00 A.M. Monday morning make approximately $16,000, part-time. According to Sheila, the purpose of these shifts, with four days on and three days off or three on and four off, is to approximate family life more closely and to allow staff and residents to have a better sense of living together. Each morning, the residents wake up with the same staff who were with them the evening before. As Sheila explains, this arrangement was something they developed after trying other shift schedules:

> It seemed wrong to me, like the institution, cold and unfeeling, to have the people saying goodnight to one person and waking up with another person. I didn't see how anybody could have any sense of being home, especially people who don't tell time and can't follow a calendar. I didn't think they could understand their future, understand what was happening to them, or what to expect. Also, I thought there were too many people in their lives. So we changed the staffing pattern. This way people can share lives together.

There are other strategies that Sheila and Steve use to ensure that the men and women they serve feel part of a home and not simply as people who are being managed by a system. Sheila or Steve visit the houses at each weekly staff change: "I guess it's kind of like passing the torch," Sheila told me. The residents are also taken to work in staff cars and picked up in the same manner rather than having this done by school busses or vans. Under state law, the local community board of education is required to provide the transportation but Sheila and Steve believe such an arrangement would be demeaning, e.g. to go to work on a school bus. And since they do not work in a typical work setting, there is no chance for them to car pool. (Integrated work remains a next goal for Sheila and Steve to achieve).

Sheila and Steve worked hard to locate parents and other family members of each of the residents. For many residents, this has occurred. They found Jill's father, although his contact with Jill has been sporadic and unreliable. They encouraged Susan's mother to do things with the people in Susan's home. It is common for her to go to movies with Susan and others. As Sheila puts it, "She's almost like another resident sometimes." They found Leonard's relatives.

While I was visiting Leonard's house, his uncle called to say that Leonard was receiving an increase in his Social Security check and to ask whether he wanted this money put in the bank or sent on to him for extra spending money. Leonard decided to put it in the bank.

The People: From Inmates to Housemates

Leonard is the oldest of the residents. He has severe physical disabilities, contractures, and a communication handicap as a result of his physical disability. He has cerebral palsy. He communicates with his eyes, straight up and down for yes and sideways for no. Simple communication is difficult for Leonard. People around him must guess at what he is trying to say. He has to be fed, bathed and dressed. He has difficulty swallowing and, as a consequence, does not weigh a lot. He can operate a computer using a head control (on-off switch). He can read and is quite bright. Sheila and Steve even wonder if he is retarded at all. When I met him I spent nearly 20 minutes telling him the story about Rosemary Crossley and Annie McDonald from the book Annie's Coming Out that details the experience of Rosemary McCrossley helping Annie McDonald get free escape from St. Nicholas institution in Australia, an institution for people with severe cerebral palsy and mental retardation. As I recounted the main events of the book he nodded and smiled at the right moments.

Mathew is 33 years old. He is labelled retarded and hearing impaired. He wears a hearing aid that allows him to hear loud sounds such as an alarm or music and understands some sign language. He rarely initiates sign language, but he will use it if others do; he generally gestures to communicate. He understands much of what is happening around him. Steve explained, for example, that if Sheila said she was going to make soup, he would hand her the can opener. He has very little

language; he can say "home" and "broke." Because he also has cerebral palsy and a good deal of spasticity, he uses a wheelchair.

David is the other man served by Westport Associates. He is 29 years old. According to Sheila and Steve, David can be moody. He has a difficult time adjusting to new staff. He loves music and can sit and listen to new albums for hours on end. "It comes above all else" Sheila explains. He has a good sense of humor. One time he recorded a winter weather report on the VCR and then played it back for Steve in August. Mathew and Leonard both have families that they keep in touch with, but David does not have family ties. He was institutionalized at an early age. He complains regularly about the Day Hab Center he attends during the day. He can also be difficult. "He can be abusive physically," Steve explained. "He can hurt you. He can kick you. It is amazing to me since one side of his body is practically non-functional. He only has one good hand and one good leg and he weighs only 98 pounds. He is strong though. He will sometimes scream profanities for 10 or 15 minutes."

Debbie is 43. Sheila considers her "the most comical." She had been in the institution all her life. Debbie is "really bright," Sheila explains, "she loves to do things and she loves to go places, loves people and loves to know that she has a lot of friends. She is quite capable." She pays attention to the form and style of what she sees others do, and lots of times she'll try to copy what she observes. For example, Sheila described a recent incident: "Once she prepared 12 eggs for one

person for dinner. She came out of the kitchen after being left alone in it for two minutes. She said, "I did dinner for you." Meanwhile, in the kitchen is a big pot on the stove filled with water and 12 eggs. The point is she tries. She likes to keep track of where things are in the house. Sometimes she wakes up in the middle of the night and gets in a conversation with herself that becomes louder and louder, more and more heated. And sometimes she bangs the wall by her bed in the night. At the institution and after she left, she had a problem holding down food. Now that she eats bland foods, that problem has subsided.

Donna is 42 years old, but looks older than that. She has white hair, can read a little, and can write a few things. She does not participate a great deal in the life of the house where she lives. She tends to sit quietly or stand on the periphery of what others are doing. Sheila says of her, "She prefers to be left alone and hang out." She looks perfectly neat, and quite controlled. When she first moved to the house, Sheila might ask her to go and get a hairbrush in her room, watch her leave the room and then wait for about 10 minutes and not see her return. Now, nearly all of the time, Donna would be able to do what she was asked to do.

Sally is 46. She is hard to understand but she seems to be more intelligent than her housemates, Donna and Debbie. She likes to be involved in social activities. She likes to go out. She enjoys camping, sailing, canoeing. She likes to participate in house chores. The day Sally left the institution, she shed

the nickname that attendants had given her. She told Sheila and Steve, "I'm not Bumstead anymore, I'm Sally."

Susan is 29 but she looks much younger. She is slightly overweight and is nonverbal. She will respond to signs and to language, but she does not initiate signs.

> When she first moved into the house, she would sit on the floor and drool. Now she feels comfortable in the house. She never does those things. She moves around the house freely, looks at books or television, comes into the kitchen to see what is going on, and looks like anyone else. Yesterday, we told her to go brush her teeth, and she came down because the toothpaste was all screwed up. She brought the toothpaste and toothbrush and she went up to Kathy and stood there. I think that is asking for help; that is communication. She never would have done that five years ago; she wouldn't have even gone for the toothbrush and toothpaste. When you look at Susan she often just looks straight ahead. She nearly always seems almost totally passive.

As Sheila explains, you have to speak loudly and animatedly to get her to respond (e.g., notice) at all.

Kathy is 40 years old. She is very thin, has curvature of the spine, and has had serious medical problems related to the spine since coming to the home. Yet recently she has seemed healthy. She eats well. She has speaking ability. When she first moved into the home, she would hide in the corner, shake, and even shriek. All of those behaviors are now gone. She is

social now, even gregarious and flirtatious. She communicates her interests well. She's a lot of fun.

Pat is 29 but looks much younger. She has a high pitched voice. It is as if she stopped growing. In fact, she acts like a child most of the time. When she was three years old it was discovered that she had a cyst on the brain. After being operated on she lost many of the skills she had and was determined to be retarded. Out in the community she will sometimes cause a commotion by shrieking if she does not get her way. Sheila describes a typical scene:

> In stores she can cause a commotion. She will get everyone in the store to come over to us. She will scream and pull on people's arms. We have to go one-to-one with her in the community. You have to give her a lot of verbal support. I can see her eyes scanning, (I'm thinking) like Who she is going to go after. I say, Pat, I don't want you to talk to that woman. It's going to embarrass me. I can't deal with it. If you want to go out with me, you can't embarrass me. If you do that, we are going to go back to the car and go home and not buy your shoes. She says, All right, Sheila, I will be good. If you lose her, if she gets to do it before you can stop her, forget it. If you try and stop her then she will have a fit. If you put your arm on her and say Please don't do that, she will scream at the top of her lungs, You are hurting me.

Pat is at once fascinating because she is so often in control of her environment, albeit in a way that can be trying, and she is exhausting, for she nearly always repeats herself in conversations with people over and over again.

Jill is 35. She is tall, the most adult looking of the women in her house, and one of the brightest. She can speak, but she is also shy and, around men, can be silly. When I first met her in her home, she looked away and glanced back at me repeatedly, as if she was being coy. At first, she had a hard time getting along with the other women in the house. She bullied them, and physically attacked them. She resisted the routines of the house, balked at going to work, and bridled at other demands made on her. As these behaviors have improved so have her relations with the others. She likes to look at books, though she does not read. She enjoys new clothes, paper cutting, putting on makeup, going out to eat, and dancing. She does not like people bossing her around.

Dinner at Home

The group homes look comfortable. They are carpeted, well furnished with sofas, easy chairs, bookshelves, dining room sets, television, flowers, and have art on the walls as well as pictures of the residents engaged in different activities. The kitchens are fully stocked. There are no charts on the walls or other markings that would distinguish these from any other homes. When I visited the home in which four women live together, they were gathered in the living room awaiting my

arrival. Each had dressed up a bit since leaving the Day Hab Center (the daytime program they attend) although all were casually dressed in skirts or slacks and a blouse. Those who could talk, Pat, Jill and Kathy, introduced themselves. Susan put out her hand after some prompting but did not look at me when she did. Pat asked me if I wanted a coke:

Pat: Doug, would you like a nice cold coke? Doug, a coke on ice?

Doug: Thanks, but you know I'd rather have water if you have it.

Pat: Coke, Doug? Want a nice cold coke, Doug? A coke on ice?

Doug: (I smiled and said) No thanks, but I'd love a cold glass of water.

Pat: No coke, Doug?

Doug: No thanks, but I'd love water.

Pat: Water it is, Doug.

We had a barbecue together that night on the back porch. The food included steak, potato, vegetables, and sodas. A couple of times when Pat spoke loudly in her high pitched voice, presumably to compete with Jill and Kathy's conversations, I wondered if the neighbors might complain. Except for these brief moments of concern, the evening was uneventful. We talked for several hours about work, life at home, and life in the community. I told them a couple of stories about what had happened to several people who have moved out of institutions and who are now living on their own in apartments with a modest

amount of support. They were very interested, excellent listeners, filled with questions. Occasionally Pat interrupted to say "You are a good story teller, Doug." And at other times during the dinner, Kathy remarked repetitively, "I'm full, I'm full." Yet she kept eating her meal, slowly. Each of the residents was able to get her own dish of food and bring it to the table. Jill slipped while taking her empty plate to the kitchen, but one of the other women helped her clean up the spill.

I came away from the meal and visit feeling that this was very much a home, the women's home, and that they were proud and pleased to have a visitor. They knew how to entertain.

The same person, different times

Throughout the visit, Kathy was in good humor. She showed me her room and some of her pictures. She smiled and laughed during the evening's conversation. She exuded an air of satisfaction.

The next day I had an opportunity to read some of what had been written about Kathy in her institutional records. These reported the circumstances of her admission to the institution:

> 1963: Kathy began to scream when she arrived at 9 A.M. and continued until 11 A.M. She ran about the room, constantly; was reprimanded and spanked frequently. She is a tall thin unattractive girl.
>
> Diagnosis: mental retardation, severe, etiology
>
> Recommendation: admit to building # 12.

. . .

Kathy is an unattractive 8 year old youngster who functions at the moderately to severely retarded borderline (IQ 21). Her speech is minimal. She has tantrums in her behavior here, screaming and crying, appears disturbed. She has a large head indicating organic impairment. Mother has taken good care of this youngster. Recommend admission. At the present time, she is home all day, hyperactive, screams, gets up during the night and wants to play, cannot go outside as she wanders away and is generally a serious responsibility for her mother and stepfather who has accepted her apparently without reservation. Mrs. Thompson bickers and fights a good deal with her neighbors because Kathy is teased by the neighborhood children and even from her own relatives and has general discord in the neighborhood because of Kathy.

1966: She cares for herself at the toilet and at the table except for cutting meat. She undresses but cannot even put on socks without assistance and needs help washing her hands and face. Kathy plays by herself but cannot play with other children without teasing or quarreling and cannot be depended upon to carry out simple tasks or to run errands. She is, in general, a quiet child who speaks very little and needs a great deal of supervision. In view of her higher IQ, it would seem beneficial for an effort to be made to teach Kathy to talk for herself to a greater extent and to play cooperatively with other children.

Mental retardation, moderate (IQ 35).

1976: When Kathy visits her mother during the Christmas holidays, her brothers and sisters will come to the house to see her. She will also go out to visit family and friends. They will take her wherever they go. However, she always wants to go back home. She is afraid that she is going to be brought back to the school and wants to stay home for the entire time and does not really enjoy visiting other people because she is afraid that she is going to be brought back to Dever before the weekend is over. When she is home she really enjoys music and spends most of her time listening to records.

1976: Recommended program: Custodial care, developmental program.

In the face of little or no support in the community, Kathy's mother had placed her in the institution. If the official records are to be believed, Kathy's time at the institution was difficult. She was dependent, isolated, and perhaps even fearful. Little was done to draw her out or to help her develop. As the accounts of her home visits indicate, she wanted a home alone and knew the institution was not a home.

Being in the community/Being part of the community

As I talked with the four women at the Mohawk Road home, I learned about each person's interests and activities. Every one participates in food shopping on Monday. One of the women attends a cooking class once a week. And each of the women gets

to go out to an activity or a place of her choice alone with a staff person at least one evening a week. One might attend art class, another exercise class, and another bingo or camping groups, for example.

The purpose of each of these activities is that they will lead to the women developing friendships in the community. That has occurred only marginally, but it is a condition that Sheila and Steve are determined to reverse. This issue came out in many of my discussions with Sheila and Steve. Sheila discusses Jill's situation:

> I am good at providing people with the feeling of stability and being a part of something and being an important person and having people care about you and building people's confidences and also getting their medical problems under control and their bodies under control and their looks under control and getting them decent wardrobes. That took years, and now I think that they have all that and the emphasis needs to be outward. If a person went to the "Y" every single week, we thought they would meet somebody there and that our staff would be bridges to those people or that maybe they would have coffee afterwards. It has not worked out that well. It has been a struggle. I think the people are truly physically integrated. People in the community know them and are friendly. But we haven't been able to get them friends. We haven't been good at that. I think one of the problems is the work situation. If Jill was working in a day care center, she was the only disabled person there

among twelve or thirteen other staff people, maybe somebody would really like her and invite her some place. Jill picks up a baby, puts it on her shoulder, walks around the room patting it, and she is in seventh heaven. I am sure that there are day care centers that would need babies to be picked up. She is very calm, gentle, and loving of babies. One of the staff who worked here on weekends just had a baby. Jill gets to spend a lot of time with the baby on the weekends. So Jill has friends with staff and former staff. In fact, the former staff spend a lot of time with the men and women. One of our former staff has invited three of the women to her bridal shower and to her wedding. A few weeks ago, she showed up to go to a concert with them. One morning I asked her if she could drop one of the women to church, and she said sure, no problem.

But we really haven't been able to get people friends.

A Business or a Home?

Many community service organizations view their work as a business. Sheila and Steve reject this approach. They insist that the business demands of running a service be secondary to the cause of creating good homes. They are willing to compromise on business matters in order to accommodate the goal of quality community living. When, for instance, Debbie came into repeated conflict with Donna, they had to make a decision about living arrangements for them. This problem came at a time when they had to move from the Drift Road house anyway because the landlord was

overcharging. It was an opportunity to deal with a troubling situation in the house. Should they continue to have Donna, Sally, and Debbie live together? Should they switch Debbie and another resident from another house? Should they find a separate apartment for Debbie? And, if they were to do the latter, how would they afford it? Sheila explained the situation this way:

> The basis of the problem was one woman's personality and how she interacts with other people. Debbie is a wonderful person: she is amusing; she is funny; she is bright; and she is a bottomless pit for attention. She has been so deprived, so rejected, and so damaged psychologically in the past. She is very jealous of the other two women. She tries to drive them crazy. She chose Donna, quiet Donna, as her victim. She perseverates on Donna, saying, "Where's Donna, where's Donna, I want to see Donna," even when they're in the same room together. At other times she would repeat, "I'm going to smack Donna, fat cat Donna." Debbie would hover around her and physically abuse her. But she would do it in a way that you were never really sure. She would say "I like Donna" and be giving her a hug and would then yank her hair or scratch her. She would perseverate, saying "Where's big fat Donna." Donna is actually slim. She would make fun of Sally, calling her "Bumstead."

Even though it would be more expensive than operating a single house, Steve and Sheila decided to look for a house that had an additional, separate apartment, thus allowing Debbie to have her own living area but also allowing for joint activities by the

three women. This would cost more in rent, possibly, and would cost more in staff, but it would accommodate to the situation that faced them. Their local banker had come to know the program. He helped find a landlord willing to rent to them who had a ranch style duplex available. In retrospect, the search for a new home that could accommodate Sally and Donna on the one hand, and Debbie on the other, was a test for Sheila and Steve. Sheila believes they passed the test:

> You have to put your money where you think it is important. We could have lost Debbie. If Debbie hadn't been with us, we wouldn't need a new house; just send her to a specialized care home. But we do not have termination policies. No one gets terminated. If someone needs something else, then we provide it, unless they don't want us to. If they want to stay with Westport Associates, we will do whatever is necessary to keep them. The 10 people that we serve are Westport Associates. The agency should be flexible. People shouldn't have to fit into it.

The cost of running Westport Associates is approximately $35,000 per person per year (1986). That is a fraction of the cost of institutional care. Sheila estimates the per person cost of Dever at $80,000 per person per year. At Westport Associates each of the men and women contribute $265 per month, $70 toward rent, and $41.55 a week for food, all out of their supplemental security income (SSI). That represents between 65 and 70% of their social security. The (State) Department of Mental Health

pays $313,000 per year to Westport Associates, and also allotted $11,500 for transportation.

Virtually all of the budget goes for staff, health insurance, liability insurance, utilities, staff mileage expenditures, household appliances and other odds and ends. Sheila and Steve each make only $2,000 more than the house coordinators. Sheila explained the reasons for the Westport Associates' pay scale:

> We have always had the philosophy that we didn't want to run an agency where the directors make $35,000 and the staff make $10,000. Sometimes it (the policy on paying coordinators $21,000) works against us, an incompetent person may stay for the money. Most of the time it really works for us and for them, to see this as valued work. It is hard for people in society to see this as valued work, "living with the retards."

At a more fundamental level, the pay scale for staff reflects Steve and Sheila's valuation of residents. Sheila and Steve regard the work as important, worthy of good pay. Part of its importance is in the responsibility associated with it, and part is in the nature of the work itself:

> I want to run those houses. If I don't show up for three days, I want them to survive and make decisions on their own. They are caring for very vulnerable people. There is a lot of responsibility involved. If somebody gets hurt or upset, they have to be able to deal with it. They give up a whole week of their lives living with other people and I

> all of that equipment where they put those electric things on your heart. I stood up and they pushed me out the door.

Kathy was scheduled for surgery the next morning. But when Sheila came back at 7:00 A.M., there she was sitting up, laughing. This all happened nearly three years ago. Since then she has remained in good health. Sheila and Steve still worry about her when she gets a cold; they worry she might get pneumonia. But as Sheila explains, "We try not to over medicalize her." When I met her, there was nothing in her behavior or how others treated her that would suggest she had a special medical problem.

It is impossible to consider such accounts or to observe the homes without recognizing that Sheila and Steve's lives have become intertwined with the people in the homes. Steve's wife used to work in one of the group homes. Her children from a previous marriage have grown up knowing many of the people from the homes. Sheila brings people from the homes to her home to visit regularly. Donna does her laundry at Sheila's house. There is no clear line where the program ends and Sheila or Steve's personal lives begin. As Sheila explains, the two may not even be separate at all: "On the one hand, I could say it has a really big impact on my private life and on the other hand I can say that they are my personal life." Clearly Sheila has other interests, a network of friends, and social outings that do not include people from the homes, but the people in the homes are among her friends, part of her network.

think that they have to be rewarded for that. Our salaries have always been higher than anyone else's.

Also, since they hire mostly women, they have decided consciously that they do not want to contribute to the problem of women being paid proportionally less than men for their labor.

They look with cynicism at others in the field who have become more like business operators than service providers:

Mega agencies are these companies that run workshops and residential properties all over the place, in Fall River, down on the Cape, in Worcester, New Hampshire, and Rhode Island. Two guys we know started in service but then they set up this huge thing where they are a for profit real estate business. They have a contract with CARES, their original service agency. They manage the property and get all this administrative money but have no liability and no responsibility. A friend of mine had dinner with them and was just shocked. All they talked about was how good they were doing, ripping off the system, making all this money, how they had it figured down to a Tee, to get all this money with no responsibility.

Sheila and Steve shudder at the thought of seeing their work as a business, although they believe that this business orientation grows out of the fact that there are so few people willing to run quality programs. For them, this is not a business. It's more a way of life: "What I have done with these 10," Sheila told me, "is all like family. You wouldn't decide one day to leave your family and then have another family

somewhere else." The work is not all sacrifice either. Sheila and Steve obviously enjoy their jobs. "Of course I like it," Sheila told me, almost apologetically, "I wouldn't do it if I didn't like it. If you have to earn a living, what a wonderful way to earn a living to see other people become happy and enjoy life."

Day Hab: A New Kind of Institution

Four and five story brick buildings, smokestacks, a nearby river and a wornout look make Fall River a classic old mill town. The town remains largely as it was, a conglomeration of industrial buildings mixed in with woodframe homes, large ones on the town's hills, modest ones close by the old factories. Growth around Fall River is happening outside the town, in suburbs that house people who work in Providence and Boston.

Set in the midst of the old factories and warehouses is a low slung, one story, beige building, the "Day Hab Center." Fifty-four people labelled retarded come to this building each day for treatment programs. Among the clients are nine of the Westport Associates residents; only Sally attends a different program. She goes to a sheltered workshop in the area.

The Day Hab Center is funded with federal Medicaid dollars. This funding law prohibits participants from being involved in work more than 20% of their program time and requires active treatment and therapy instead.

The director is a man about 40 years old. He described the first two rooms I saw as part of a prevocational program. I saw people labelled retarded sitting at tables doing wood puzzles, looking at a U. S. map, playing the card game Uno, and sorting colored chips and nuts and bolts. One man had his head down. The doors to the rooms were closed. As the Director opened each one and we peered inside, I could not help feeling that the rooms looked barren, with the people, furniture, and materials somehow disconnected to it; it looked temporary: folding chairs, sparse furnishings, and people who looked bored. In the next room, the Director explained, was the Adult Daily Living curriculum. A resident, Kathy, sat alone, holding a hair brush. In another room a man sat at a computer that he could activate with a switch. A woman holding a white handbag sat in a rocking chair rocking. As I walked down the hall, past the physical therapy room---the therapists were sitting down next to a one person trampoline, two women sat on stationary exercise bikes, and one woman sat on the edge of a gym mat, next to a balance beam--- several of the residents showed us their projects from shop, a plant holder, spice racks, hot pan holders, and tile trivets. Debbie had Maalox on her nose; one of the people I was with helped her wipe it off. In a third area, by far the largest room, perhaps 30 by 35 feet, was the "transitional program." I watched while five clients sorted pieces of black metal with holes into manila envelopes. Another group sorted butterfly labels into plastic bags; some of the plastic bags were ripped so that the labels fell through the bags. These materials were

apparently remnants from a real sheltered workshop contract; the materials were being used at the Day Hab Center to simulate work. In the late afternoon, staff take apart and unsort the materials so that clients can sort them again the next day. Is this work? Is it a simulation of work? It seemed like make-work.

The Director explained that he was not fully satisfied with the program. Some of the older clients should be out in geriatric centers, he explained. He thought the Center needed more real work. And he came to the fact that too few of the clients had the kind of support at home or in residences that was given to the Westport Associates people. "They're the best dressed" he told me, "they get to go to concerts every weekend. The others here are lucky if they ever get out. When they do it's in a bus or van for 15 on a trip to Plymouth's Rock." He did not mention the Day Hab program as a problem.

The Area Director for Mental Retardation who is responsible for coordinating, approving funding for, and monitoring Westport Associates, the Day Hab Center and all similar services in the area did question the program. In fact he told me that it embarrassed him. While his agency funded the Day Hab Center he said he wanted to see it phased out. "I just have to make a lot of apologies for that (the Day Hab Center). It has to be real culture shock" (for the residents to go from Westport Associates homes to that Center each day.)

Sheila and Steve concur. They too see a dramatic discrepancy between the day program and their homes. "They even have a program" she explained sarcastically, "on Friday afternoons where for two dollars each, the clients can stay and watch a video on a VCR. They say it's so they can learn to relax." From Sheila's vantage point, television has been about the only form of recreation many of these people have ever had. She finds it ironic that watching television would be called a program to teach relaxation. Sheila finds the Day Hab Center reminiscent of the institution. "Everybody is required to bring two sets of clothes each day," she explains. "It's as if all of the people are assumed to be alike and that it's expected, it's okay to ruin clothes." When Susan had a toileting accident once, the staff at the Day Hab Center asked Sheila and Steve to supply diapers. Sheila tells this story angrily: "Why not just remind her to go to the bathroom? How hard is that? We send them in the morning looking good," Sheila complains. "They don't look like that when they come home."

Neither Steve nor Sheila holds out hope of the Day Hab Center changing from its seemingly custodial orientation. Sheila explains that they want something altogether different: "I want someone to open a supported work program (placing people into typical employment situations and supporting them with job coaches so that they can participate partially or fully in the work activity). "Here they learn to dry dishes and wipe tables which they can already do," she laments, "it's pretty much life wasting." "The first director of the Day Hab Center tried to

play down the Medicaid requirements. In the early days there were only 26 clients. But now it's just a dead end."

She spoke with me about Jill:

> She needs more people. She's sick of looking at my face. She could be working in a day care center tomorrow, with no training. The reason why they (Jill and the others) don't meet people is that they don't work with nondisabled people. The big activity centers are the worst. Aside from the institutions, this is the worst problem, what people do with their days. It's (the Day Hab Center) basically a nursery school. And they can't even keep it going the whole day. It's supposed to last until 3:00 P.M. But everything ends at 2:00.

Sheila sees no immediate option for the Westport Associates people. "Most of these people don't need occupational therapy and physical therapy; they need to earn money. But DMH (The Department of Mental Health) tells us to send people there. It doesn't cost them anything (or little since the program is Medicaid funded)." Sheila regards the only short-term option as lobbying for individuals to get out into different situations. Again, she spoke of Jill: "We advocated to get Jill out. But she's still here. It's like a life term when you come here. They (all of the people in the Day Hab Center) are stuck here, but," Sheila continues, "it's not my bailiwick. I can't do it all."

A Program or a Home?

Community residences have numerous competing agendas imposed on them. One that we have already discussed is that they must operate within a budget, like it or not as a business. Another requirement is that they meet certain government regulations. State rules, for example, require the home to operate as a training program, indeed almost as a classroom, whereby each resident has a book filled with charts and goals, "behaviors" to be taught, objectives to be met. Each resident needs an "individualized service plan" that is comparable to the public school requirement for students in special education to have individual education plans. Steve Murphy is the program director for Westport Associates, therefore his job includes responsibility for these programs. In consultation with staff, Sheila, and officials from the state, Steve develops individualized service plans, objectives for each behavior, a style of teaching the men and women the desired skill, and means for monitoring the instruction and its effects. These programs call for instruction in such areas as cooking, activities of daily living (ADL), and community involvement or integration. The intent of these formal programs is to encourage staff to be "fairly formal" in focusing on them. But, as Steve suggests, it is difficult to be so formal since formality in instruction takes away from the relaxed, family atmosphere that they try to create in the homes. The state requires a report every four months that indicates the skills, the steps that it was broken down into for instruction (task analysis), the time spent on it, and the

results. Steve says this is "not the main focus of my job. Maybe I have had it in my mind that this was paperwork that had to be done and it was more important that they have their home and enjoy life." Sheila elaborates by explaining, "I don't know if we would say we are so big on that kind of structure. We have this philosophy that it is a home, not a school, not a program. We never intended to get terribly structured." During my visit, I heard staff discuss areas or skills that individuals were working on, for example, becoming more independent in helping to set the table, developing other leisure activities besides listening to records, and keeping neat. But these were naturally worked into the routine of everyday life.

What comes through in the homes is the sense of the residents, the men and women, being treated as individuals. When Sheila and Steve involve themselves in the lives of the residents, it is not for the business or for the regulatory demands of the state. "Sure I worry about whether we'll have enough money to stay open (the State is late each year in paying the first month's expenses) but," Sheila admits, "what really bothers me is if I go over and take Pat's shoe off and look at her toenail and find it has not been cut for 2 months." She adds, "Then the next day I am running out at the last minute for ball gowns. This is important to me that they look nice for that night. At the last minute, Jill's necklace broke and I am on the way to the mall with her to buy a new necklace. I think those things are really important."

A sense of community and stability in the homes has been consciously fostered, especially in situations that would cause stress. Moves from one house to another could prove traumatic. But as Sheila explains, even a change of houses can prove uneventful if carried out thoughtfully. She described a move of Jill, Kathy, Susan, and Pat from their first home to a new one:

> We thought about what it would do to the women to move. I worried and fretted. But the women didn't mind the move, they were great. We moved in one day and we did it ourselves. All our staff people helped. We had people packing and unpacking and moving. The first thing that we did when we got there was get the rooms ready. Kathy kept saying "'ed, 'ed" pointing to her bed. We got pictures on the walls and personal items arranged in rooms. That calmed everybody down immediately. The second thing that we did was set up the living room very much like the living room in the other house. Those women never batted an eyelash. I think that's because we achieved the goal that we had set for ourselves in the beginning which was giving them a feeling of security and stability and that change could happen but that nothing bad was going to happen to them. They moved together, we were with them, and they had each other. They still had their own stuff. I felt that we had done a good job over those three years, that we had supported them well. I was proud of them.

As I observed in the homes and met each of the people, I quickly became aware of a concerted effort by the staff and by Sheila and Steve to get people active in the community. One person attends exercise classes at the Y. Another goes to church. Another is an avid camper and belongs to a wilderness organization.

Each of these activities, as well as virtually every other aspect of the men and women's lives, becomes evidence for Sheila and Steve, as well as for the other staff of Westport Associates, that they are successfully escaping the effects of institutionalization. We noted, for example, Susan's transformation from a person who sat on the floor and drooled to a person who wants to be around activity in the home, who participates in household chores, who now looks at books and, like the others, looks very normal. Staff report that her mother is amazed at her change. Susan was institutionalized when she was three or four years old. At that time, she is said to have been able to speak. But now she does not communicate verbally at all. Instead of labelling her noncommunicative, however, the staff regard her as communicating through gestures, through her presence in a group, and through her seeming happiness. Sheila comments on Susan:

> I have dreams that Susan talks, and that she is in musical comedies, singing and dancing on stage. She is very bright. I and everybody that has worked in that house have had dreams that Susan has talked to them. She seems to hear when you say her name. We gesture and use signs with her a

lot. If you tell her to go wash her face, she'll go and do it, whereas five years ago, forget it, she wouldn't do anything.

This enthusiastically positive view of residents surfaces again and again. Jill came to the group home with belligerent behaviors. She threw Kathy down the stairs, punched her in the face and stomach and hurt her so badly that she had to be taken to the emergency room in the middle of the night. She could be "really ugly and unpleasant." She too is seen as transformed. She no longer attacks other people. She is nice to be around. About the only remaining difficult behavior is that occasionally she will take something, a book, for example, from another person and toss it. She has become helpful in the house, even helping the other residents when they are in a hurry to go somewhere. Sheila now describes her as "totally different, good, nice to be with."

Sheila says of Sally, "When she walked out of the institution she never looked back." Perhaps because Westport Associates represented a total change from institutional conditions, the people changed. Kathy's transformation, like that of the others, reflects a rejection of her past and of the behavior that marked that past. Now, she appears as perfectly pleasant, humorous, and confident. Sheila explains the change:

When she first moved in, she was very fearful and would stand in corners and do bizarre flapping things with her hands and keep saying 'it hurts.' If anybody would go near her she would do that. The second day, I came in and saw

her laying on the couch very relaxed. She got used to living here very quickly. Now she is not fearful at all. We used to hate taking her places ---she would be fine and we would be eating, then suddenly she would get up and go back into a corner and start flapping. We thought we would have to have a very structured program for this, but it went away. I don't know exactly when it went away or why, but it did. She is becoming more of a person. One day Donna, the social worker from Dever, who is a very nice person, came to see the ladies. Kathy took one look at her and bolted for her bedroom upstairs and hid in the closet. I think she thought the social worker had come to take her back. She had always liked Donna at the institution, but she would not come out until she was in the car.

Lives intertwined

The nature of Steve and Sheila's job, as well as that of the house staff, is that they are constantly on the go, fixing equipment such as dryers, washing machines, toilets, and other household items, painting rooms, finding decorations with residents, locating family members, and taking care of health related matters. This latter activity, health, takes considerable attention. Whenever the men need to go to see a doctor, Steve takes them. Sheila takes the women. Some of the residents see four or five doctors, for example an orthopedist, audiologist, family physician, dentist, and ophthalmologist. And some of the men and women have had severe health crises. Kathy,

for example, was hospitalized for seven weeks, much of it in intensive care following a risky operation related to her curvature of the spine. Pat has had three hospital stays for brain surgery. David was hospitalized for two or three weeks for epileptic seizures. These hospital stays can be taxing:

> It took a lot of energy because we don't just shoot people up to the hospital and say 'See you when you are better.' We were up every day (to the hospital in Boston, over an hour away). There wasn't one day that Kathy didn't have one or the other of us with her, practically all day. One or the other of us would go up in the afternoon, each day and stay till midnight. When Pat was in the hospital, we would bring her mother up every day.

Obviously it matters to each of those who have been hospitalized that they have people around them for support. In Kathy's case, attention during her medical difficulties may have saved her life. During the operation on her spine, she developed complications. One lung collapsed. The operation was never completed. She was put on a respirator. Then she developed connective tissue problems. She was put in intensive care and on a respirator. Sheila explains what followed:

> One night her heart and breathing stopped. The nurse had just gone to dinner. They had just extirpated her 2 hours before and she was doing fine. The nurse told me to call her if there was any problem. Suddenly she just turned a funny color and couldn't breathe. I screamed and everybody came running. Everybody jumped on the bed and brought in

The answer cannot be discovered, it must be created

On the evening after my first day of observing Westport Associates, the ABC television program, 20-20 aired a story about the Behavior Research Institute in Rhode Island. This organization is controversial among residential program operators as well as with the public at large because it employs physical punishment such as pinching, denial of solid foods and substitution of desiccated liver powder, imposition of a helmet on residents that bombards the "patient" with white noise, and for use of ammonia spray in patients' faces, and other noxious treatments. Several national associations, including The Association for Persons with Severe Handicaps, the National Society for Autistic Adults and Children, and the Association for Retarded Citizens of the United States have announced their opposition to BRI type aversive strategies, arguing that they are inhumane, illegal, immoral, and ineffective.

On the second morning of my observations, Sheila gave me her reaction to the BRI program. She was at once shocked, bewildered, and offended by what she had seen and what she had heard of the Behavior Research Institute. Like the institution, BRI represents for her a counterpoint to her vision of what Westport Associates has become.

There is nothing magical in Westport Associates, no special treatments, no rigidly codified and applied behavior modification, no extraordinary curriculum or uniquely trained specialists. Rather, they adhere to a set of principles designed to ensure that people are treated in ordinary, caring ways:

Keep the program small.

Make the homes homelike.

Involve people in community activities, community work, and community life.

Think optimistically about people's development, about their ability to change.

Avoid making community living institutional.

Give people choices over how they live their lives.

Don't let business pressures associated with running a community residence dictate whether or not people receive humane, decent support.

Don't let state regulations make homes into programs or treatment centers.

Help people find friends.

Be flexible.

Care for a small number of people.

Treat people as you yourself would want to be treated.

Create a circle of support around each person.

Do not allow yourself to become a business, driven by the pursuit of profit.

In other words, the answer to community living is not like a new medical treatment, or an unusual laboratory-like procedure, or punishment in the guise of treatment. Rather, Westport Associates' answer is to create community by helping people make contact with the community rather than by treating people in isolation from it. The fact that Sheila, Steve, the other staff and the residents can accomplish the goal of community living in

the face of considerable pressures to recreate the institution in the community, to compromise to profit motives, to accept and even apologize for demeaning day programs, or to go out of business as a result of bureaucratic delays in financial reimbursement from the state is a testament to the importance of the goal and the determination of these people.

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